

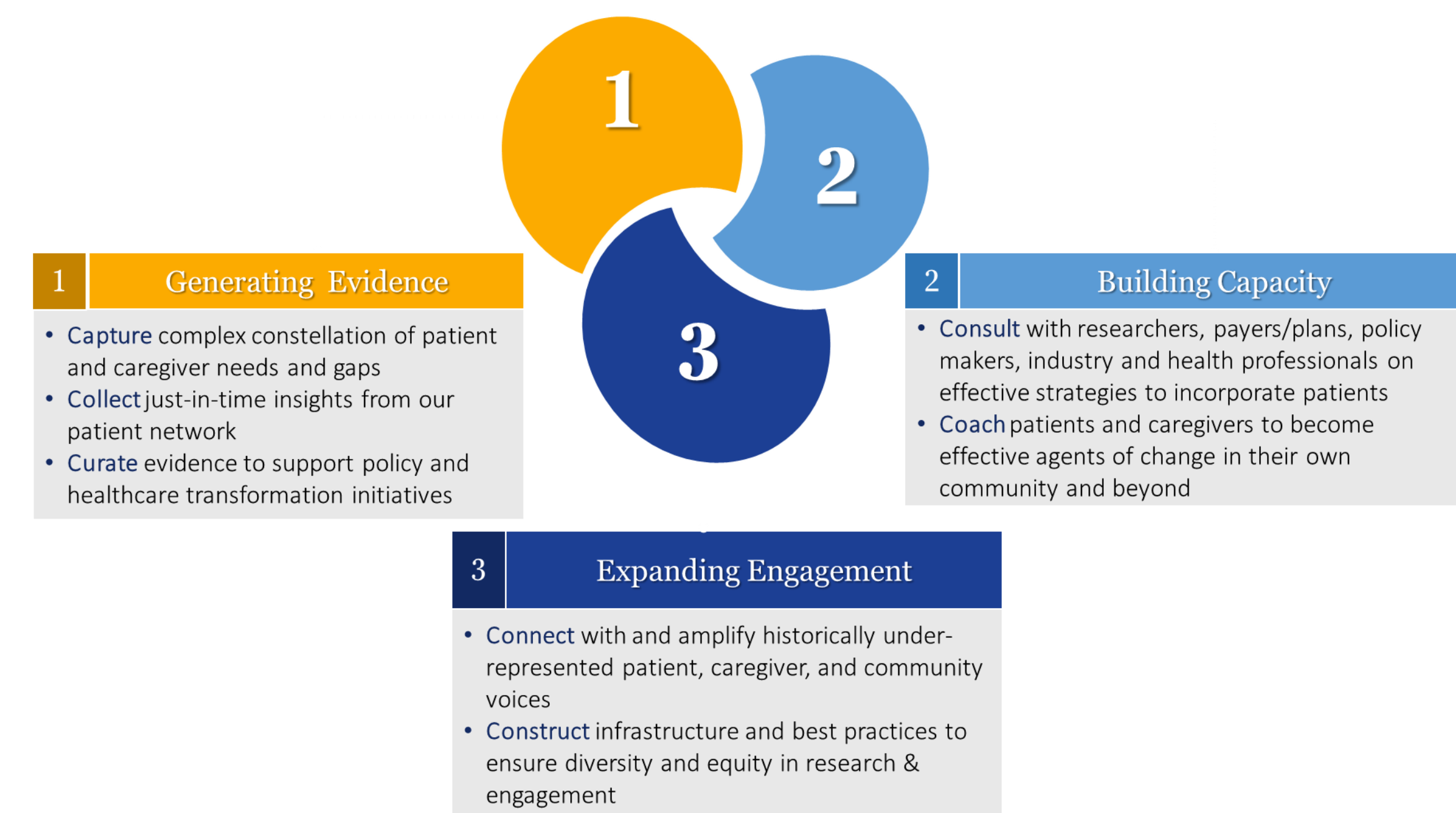
## BACKGROUND

Capturing diverse perspectives, particularly among underserved populations, is a critical aspect of high-quality patient centered research and healthcare.

Clinical and research teams often lack the resources, skills, and/or connection to patient communities to effectively engage a representative and diverse group of people.

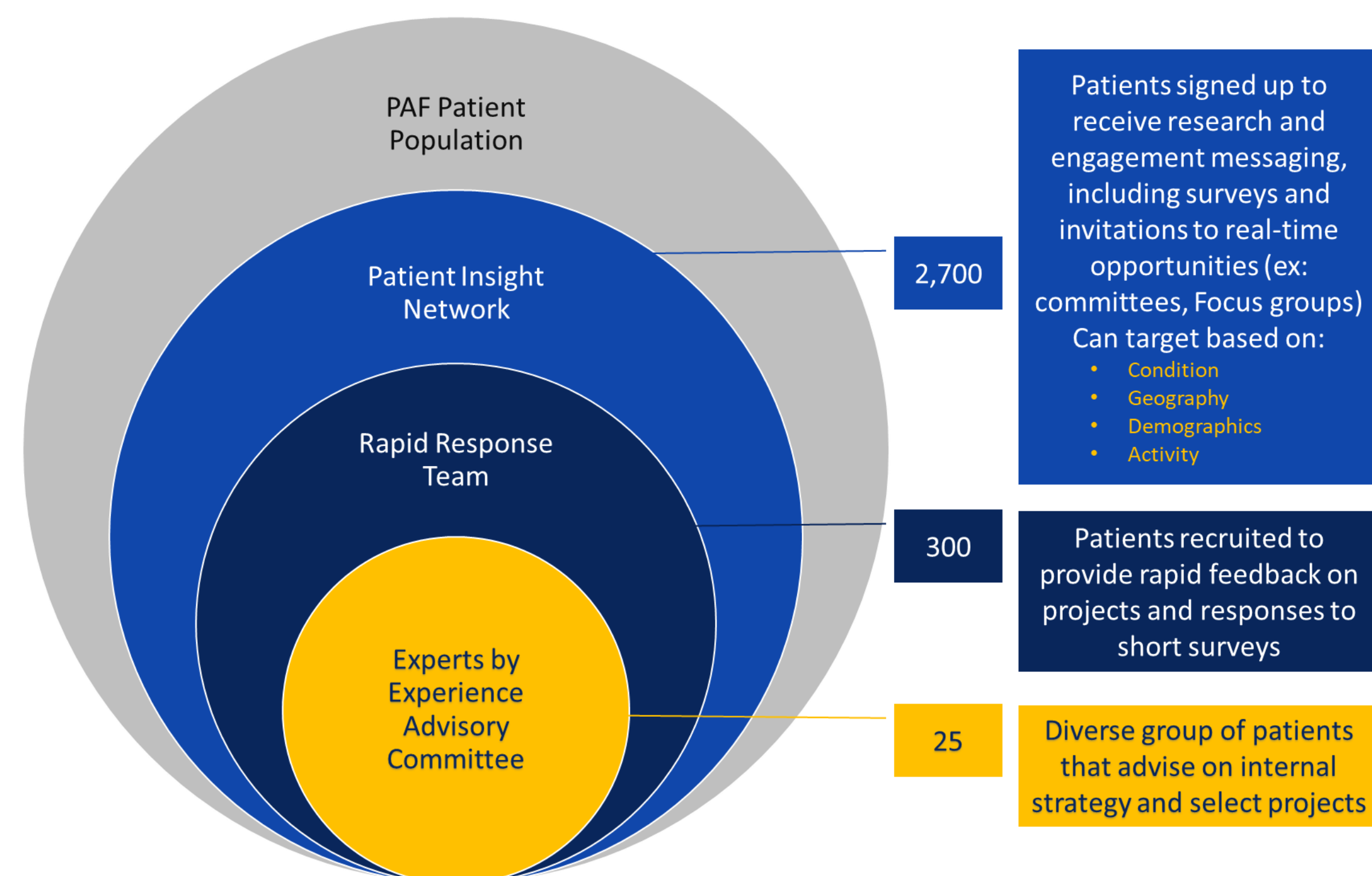
## OBJECTIVE

Provide a sustainable infrastructure that builds the capacity for patient communities, researchers, providers, and policymakers to come together to meaningfully impact projects and drive change.

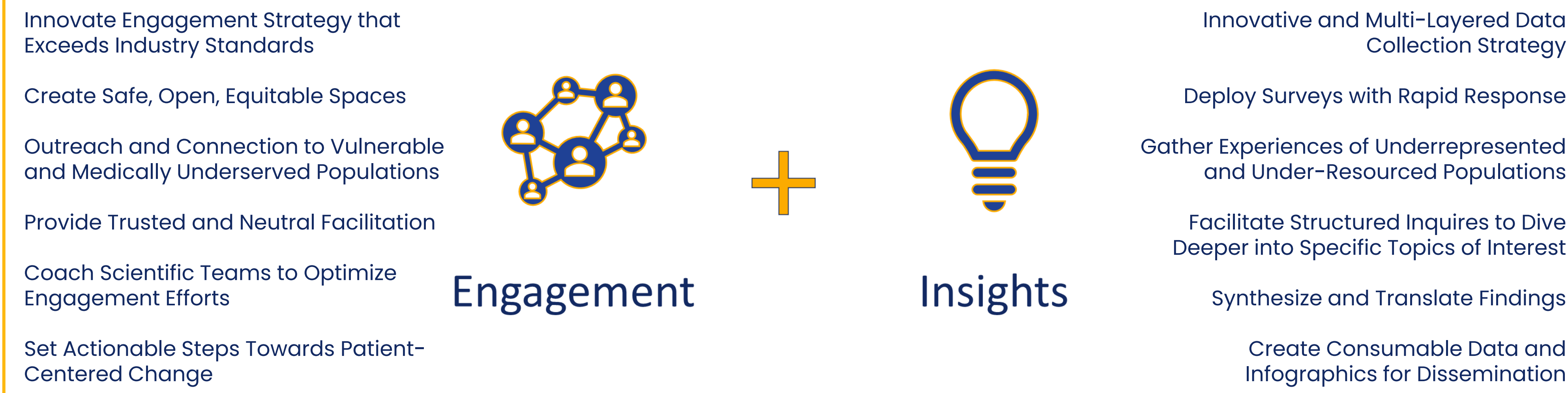


## METHODS

Our infrastructure solution combines patient outreach, recruitment, and education into a Patient Network and tailors engagement interactions to the specific interests and needs of this underserved group.



We expand the capacity of our partners to include patients in the development and co-creation of projects that meet the needs of the patient community – providing valuable patient insights to healthcare leaders to inform research, policy, and practice.



## PROJECT HIGHLIGHTS

Our *learning communities*' goal is to help ensure that patient voice influences healthcare, policy, and research.

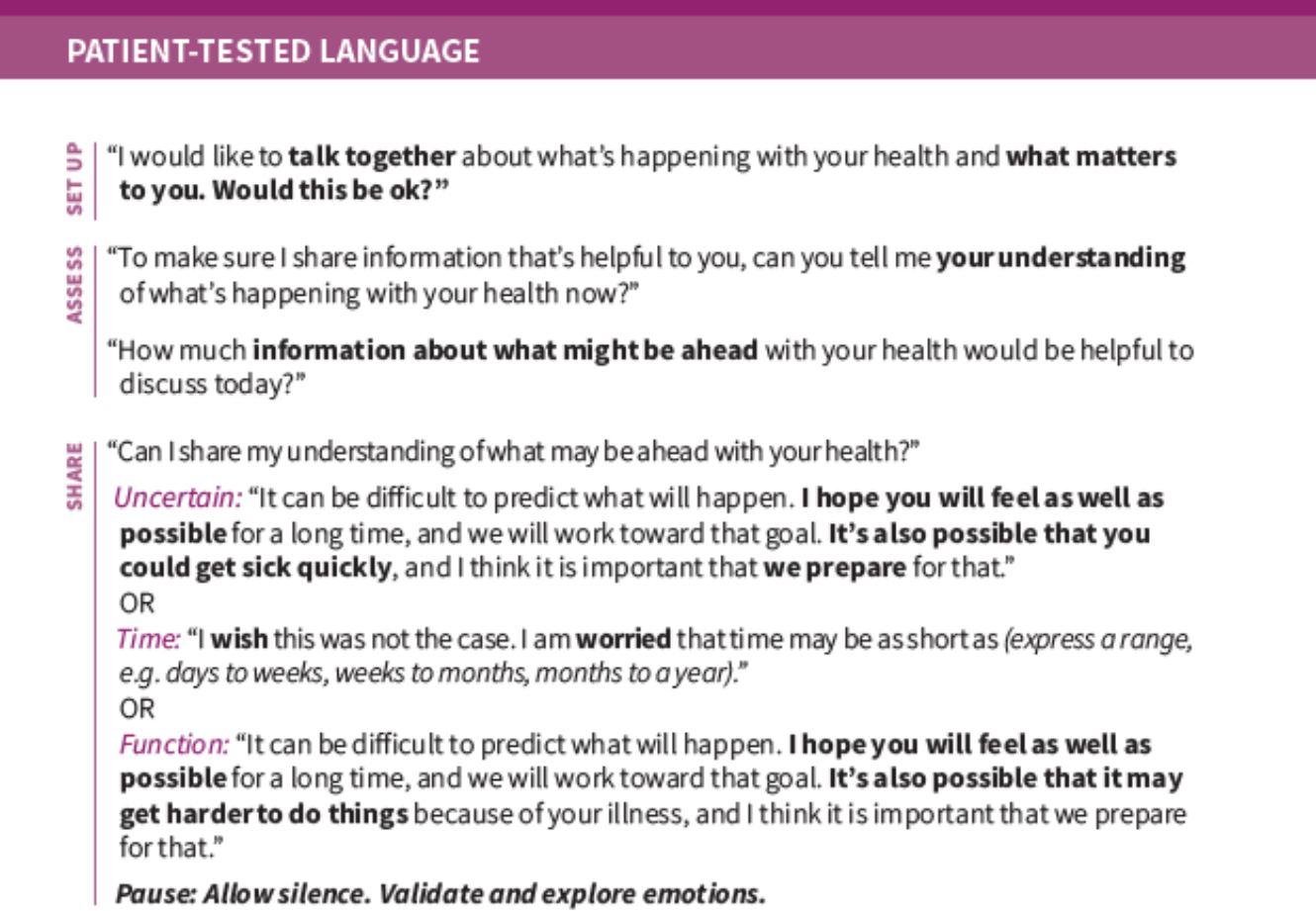


Our *Social Need and Equity Learning Community* is made up of 15 patients/ caregivers that convene 5 times a year with select researchers to discuss social need and equity related research projects and events. This group provides valuable insights to create, refine, and drive research initiatives and advise on various aspects of existing and new projects focused on the intersection of social needs, equity, and healthcare.



Patient and caregivers across Massachusetts working with researchers to ensure that our health care systems are investing in research and programs that best serve the needs of communities across the state.

### Serious Illness Conversation Guide



### Patient Engagement in Serious Illness Care Guide (SICG) Revisions

Healthcare systems have placed increased emphasis on implementing educational and quality improvement programs that attempt to ensure that patients have access to conversations about their goals, values, and prognosis ('serious illness conversations') in routine serious illness care.

In partnership with Ariadne Labs, the primary aim of this collaboration was to revise an evidence-based communication tool, the Serious Illness Conversation Guide, to be more inclusive and accessible with input from diverse patient stakeholders.

## IN-PERSON CONVENING

In 2022 we launched our inaugural *Patient Insight Congress*, an interactive in-person event dedicated to advancing healthcare initiatives informed by the whole patient experience.

Patients and caregivers came together with researchers and health policy professionals to share their insights about the outcomes that matter most to them and what they would like researchers and government officials to address through patient-centered research projects and policy proposals.



## CONCLUSIONS

Patient Insight Institute's built infrastructure is a sustainable and effective model for ensuring healthcare is informed by the whole patient experience by giving voice to those who have been historically under-represented.

We aim to empower those who both desire to improve access and affordability of all patients and see the patient perspective as critical to informing change.

## PRACTICAL RECOMMENDATIONS

Current project-specific approaches are time and resource intensive. Purposeful recruitment, understanding the value of engagement, and a shared infrastructure has proven more effective for meaningful and sustained engagement.

## CONTACT

Visit <https://www.patientinsightinstitute.org/> to learn more about our projects, partners and engagement activities or contact:



**Rebekah.Angove@patientadvocate.org**  
EVP of Research and Evaluation at PAF  
Executive Director, Patient Insight Institute

## KEY PARTNERSHIPS



### Our Mission:

Patient Advocate Foundation (PAF) is a national 501 (c)(3) non-profit organization which provides case management services and financial aid to Americans with chronic, life threatening and debilitating illnesses.